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AUTHOR	Bogdan, Robert
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ABSTRACT

The report describes the Georgia Citizen Advocacy program which links developmentally disabled persons with persons in the community who will look out for their interests. The program is commended for its emphasis on development of "advocate/protege" relationships which are often just the starting point for involving the disabled individual in a network of relationships. Three specific relationships are highlighted in the report. Conclusions include the following: the program capitalizes on aspects of Georgia culture such as neighborliness, helping your own, and independence; the staff's close relationship to the community is an important aspect of the program's success; a relationship between a disabled and nondisabled person is likely to expand to other relationships in the community; strong ideological commitment by an agency is likely to improve the quality of life for disabled persons; and people in meaningful relationships with disabled persons grow to take them for granted and derive gratification from them. (DB)

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"WE CARE FOR OUR OWN":

GEORGIA CITIZEN ADVOCACY IN

SAVANNAH AND MACON

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"WE CARE FOR OUR OWN": GEORGIA CITIZEN ADVOCACY IN SAVANNAH AND MACON

by Robert Bogdan
Syracuse University
Center on Human Policy
Research and Training Center on Community Integration
724 Comstock Avenue
Syracuse, New York 13244-4230
(315) 423-3851

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December 1987

This is one of a series of reports on programs and services that support people with severe disabilities in the community. The purpose of the series is not to evaluate programs or services, but rather to describe innovative practices for integrating people with disabilities into community life.

I had never been to Savannah. A blurred image of the old South was in my mind when I got off the plane late Sunday night. The shuttle that served my hotel was closed, forcing me to take a taxi.

A woman in her fifties, her grey hair pulled back, was my driver. By the way she drew on her cigarette and talked to the other waiting drivers I could tell she had been driving a long time. Something I asked provoked a short autobiography. She was raised in rural Georgia in a house with no running water, heat or electricity. At sixteen she developed a skin disease which required visits to Savannah. The bus was expensive so one day she came to town with ten dollars and didn't return.

This proud independent women now has asthma. She is thinking about retiring even though she has no pension or savings. But that didn't phase her as she told me: "If you grew up here like I did, with only the basics, you don't need a whole lot. You can make it. There are good people. They will look after me. We take care of our own."

During my stay in Savannah and then in Macon I met other people whose remarks brought me back to the taxi driver's comment. The idea that people have personal resources to draw upon, and that neighbors can be counted on, were sentiments I heard expressed as I visited with the staff, advocates, and proteges in the Georgia Citizen Advocacy program. The belief in the strength of the human spirit and the need to return to values which celebrate community and mutual support are at the heart of that program. Citizen advocacy in Georgia isn't just about

serving people who are developmentally disabled by linking them with people who will look out for their interests. It is about building community, about rescuing a society from a over-bureaucratic infrastructure. The citizen advocacy movement in Georgia is not "for" the developmentally disabled, it is for all people.

I visited the Georgia Citizen Advocacy offices in Savannah and Macon because our first round of visits (in 1986) to programs nominated for providing exemplary residential programs for severely and profoundly disabled children and adults taught us that we had to study relationships if we were to understand quality living. The Georgia Citizen Advocacy program had a reputation of doing a wonderful job of matching ordinary citizens (who they call "advocates") with developmentally disabled people (who they call "proteges") in ways in which caring, supportive and mutually beneficial long term relationships developed. During my visit I found those relationships but I found much more. I found an agency that had a coherent world view and a group of people with a calling.

When I contacted my would be host, Tom Kohler, I asked that I visit and talk to people who were involved in ongoing caring relationships with severely and profoundly disabled people (Georgia Advocacy serves "proteges" with a wide range of disabilities). In addition I told Tom I was particularly interested in the residential aspects of the disabled person's life and how the relationship with an "advocate" affected that.

My original purpose in visiting Georgia was not to study the citizen advocacy concept or the organizational underpinnings of the programs. These had been described before. Rather my focus was to be on the relationships between the "advocate" and the "protege," and what I might learn about what is needed to foster quality living for people who are severely disabled. While I more or less stayed true to my goal, I did talk to various people involved with the program who gave me what I thought were important insights about the conceptual and organizational dimensions of citizen advocacy. Some of this information is included in this report.

My intention was to concentrate on four sets of "advocate/protege" relationships in my visit. While this was my plan and to some extent it was executed, I discovered that although a relationship might start as one-to-one and agency initiated, as other people in both party's lives get involved, the configuration becomes more complex. In some cases the advocate's spouse or friend may become so involved that what emerges is a threesome. In other cases a third party becomes more involved with the person with the disability than the original advocate. The "advocate/protege" relationship, narrowly conceived, may be just the starting point for involving the person with the disability in a network of relationships. In addition, as the case studies of relationships will reveal, the "advocate/protege" relationship changes. At time it may be more active than at other times. At times it may be the only

relationship in the life of the person with a disability, at other times only one of many.

For each relationship I talked to as many people as I could about the relationship. Most of the time was spent interviewing advocates. The information reported here comes from tape recorded interviews, newspaper articles, newsletters and other official agency literature, and a report compiled by the Georgia Advocacy Office [Biklen, Sari (Ed.) Just Friends: Oral Histories of Citizen Advocacy Relationships. Pat Wilson's profile of Marilyn and Cynthia was particularly helpful, and I have drawn extensively from Sidnie Shaffers' portrait of Clete Bergen and the Benjamins here.].

(Although I concentrated on four relationships in my visit, in this report I discuss only three. These relationships involved severely or profoundly disabled people; the fourth did not.)

Marilyn and Monnie Brabham and Cynthia Jones

Marilyn and Monnie Brabham are an attractive modern Black couple. They dress well and are fashionable, which is part and parcel of how they make their living. Monnie owns and operates a beauty shop. Marilyn works full time for a company but owns and operates a small women's clothing store in a shop right next to Monnie's establishment.

Six years ago Cynthia began her new life with the Brabhams. She was twelve then and for six of those years she was a resident in a nursing home. Barbara Fisher of the Macon Citizen Advocacy office introduced Marilyn to Cynthia hoping to team the two.

Marilyn was appalled that such a young person was in a nursing home. She told her mother about Cynthia and said: "If I was Cynthia I would pray that someone would come along and take me out of there, expose me to the world outside." Marilyn remembers visiting the nursing home and feeding her new found friend globs of blended food that could have been hot dogs or steak.

Marilyn was only 22 when she started her relationship with Cynthia. She began taking her out for the day, feeding her milk shakes and tried her on other real food like mashed potatoes and rice. She had worked in a hospital but had no experience with a person who was as severely disabled as Cynthia. At first her mother and family discouraged her from getting involved with a person with such serious problems but Marilyn kept thinking: "If that was me what would I want?" That is still the way Marilyn relates to Cynthia. She thinks of her as a complete thinking, feeling human being who is locked into a body that doesn't allow her to communicate. If she wants to know what Cynthia is thinking she pretends that she is inside Cynthia. Marilyn treats Cynthia as she would like to be treated and appreciates what she is doing as if she were doing it to herself.

When you meet Cynthia for the first time there is a tendency to think that she doesn't think. She doesn't appear to respond to your attempts to communicate--she just sits captured by her atrophied muscles. But Marilyn sees gestures and movements that the casual observer misses or does not attribute meaning to. Marilyn says that Cynthia makes noises and laughs appropriately.

Marilyn says: "I asked her if that milk shake is good and I don't really know that she says yes but she seems to."

While Marilyn was getting to know Cynthia, Marilyn was dating Monnie and planned to marry him. She told him about Cynthia and he said that he didn't want to get involved in anything "that heavy." Before they got married Marilyn gradually got Monnie involved with Cynthia. Marilyn would take her home on weekends and go shopping, leaving her alone with him. He gradually fell in love with Cynthia. Monnie was not new to people with disabilities. He graduated from Mercer College with a degree in special education. He taught when he first graduated but quit because he couldn't deal with the way the "system" treated disabled people.

Monnie and Marilyn married and Cynthia moved out of the nursing home back home with her natural mother. Cynthia was enrolled in a school program and everything was going well. Marilyn became pregnant. One day Cynthia's mother visited Marilyn and told her that she didn't want Cynthia at home any more. At first the nursing home seemed like the only alternative. Cynthia weighed 40 pounds and was too heavy for Marilyn to lift. A meeting was arranged between various people involved with Cynthia, including professionals, to discuss her fate. There was a suggestion that people contribute money to house Cynthia somewhere but no one could come up with a "placement." Monnie was there and was getting disgusted with the whole discussion. He had seen too many people shuffled around in the "system." He just stood up in the middle of the meeting and said that all the

discussion was a bunch of bull and Cynthia would go home with them. He told those at the meeting: "We will take her. You all go back to your fairy tale lives of giving five dollars here and ten there." They decided to take her because they couldn't bear to think of her going back to the institution and being pulled out of her school program. Marilyn found a friend to care for Marilyn until her son was born, and after she got back on her feet Cynthia moved in.

Marilyn holds no animosity towards Cynthia's mother. She didn't have a support system. She lived in poverty, on welfare, and people in the neighborhood would pick on her because she had a child with a big head and skinny legs. Speaking of Cynthia's mother, Marilyn says: "I'm not here to to judge her."

That first year was not easy. According to Marilyn, Cynthia was terribly jealous of the new child. She went so far as to push herself out of her chair onto the floor. Marilyn got tough and told her that the next time she did that she was going to leave her where she landed. The next time she did it Marilyn, after checking to see she wasn't hurt, kept to her promise and left her on the floor for about 30 minutes. She explained her action to Cynthia and from that day on Cynthia was more controlled. That little incident was significant in two ways: it curtailed Cynthia's acting out, but more important it was a clear sign to the Brabhams that Cynthia understood.

Marilyn and Monnie had no experience in providing total care for a severely handicapped person until Cynthia came into their home. They sorted advice and learned by doing. Blended food was

symbolic of her years in the institution and they broke with that. They got a special spoon made and taught her to feed herself. Cynthia being more self-sufficient was a necessity. Marilyn couldn't feed her baby and Cynthia too. She told Cynthia that. At first she didn't respond and then one night she picked up the spoon and began feeding herself. Now she is on a regular diet. Marilyn is quick to add that she doesn't eat fried chicken yet but handles meat loaf, vegetables, rice, potatoes and similar foods quite well.

Marilyn, speaking of Cynthia says: "She has been such a part of our lives that she is like one of the boys. My boys think she is their sister." Marilyn and Monnie had a second son since Cynthia moved in. Their boys are now five and three and Marilyn relates that they are protective of their sister. They don't like their parents yelling at Cynthia.

While many people respond to Cynthia with love and gentle kindness that is not always the case. Marilyn tells the story of going on a family outing to a park. It was a Sunday and Cynthia, having never gone to a park before, was very excited. There were some kids playing and they saw her and ran off screaming that there was a monster. Cynthia laughed. Marilyn cried. They left the park with Marilyn feeling the heavy weight of Cynthia's rejection. Another time they were in a mall and Marilyn took Cynthia to a deli. She stopped to get her a coke. Cynthia could smell the food and responded with happy anticipation. The owner of the shop didn't think the sight of Cynthia was good for business and asked them to leave.

That kind of rejection depressed Marilyn. She couldn't handle people dismissing Cynthia without giving her a chance. For a while the Brabhams couldn't find a babysitter. They could find people to stay with their sons but these babysitters didn't want to be bothered with Cynthia. This aggravated them to no end.

Those were real bad times. Marilyn knew that she either had to get Cynthia moved out or change her attitude. She went for counselling and finally came to grips with it. As she puts it, "These other people have problems not Cynthia, not myself. If they can't deal with her then there is nothing I can do to change them." After that she just wouldn't take her to places where she knew people might reject her.

Marilyn has observed changes in Cynthia. She is growing, becoming more mature. Her attitude has changed. She has not put on any weight but she doesn't do a lot of the childish things she used to do. She doesn't play with a baby rattle or sit and make finger motions in front of her eyes. She likes to watch TV, the Jeffersons is her favorite program, and be around people. As Marilyn puts it: "She has just grown up."

Marilyn treats Cynthia differently than when she was first involved with her. She used to treat her like a baby, hold her on her lap and kiss and rock her. She came to see that Cynthia is now a young woman and she has to be treated that way. She sees with Cynthia, as with her other children, that she has to give her room and not be overly protective of her.

The Brabhams dress Cynthia like any stylish young woman would dress. She wears jeans and has pierced ears. Monnie styles her hair and sees to it that her clothes are coordinated, a far cry from her appearance in the nursing home.

Marilyn talks to Cynthia: "We talk, I mean I talk to her and she responds. She tries to call my name. I answer her. She spends time in the kitchen because she loves to hear those pots and pans. She sits in that room and yells. She is in there with me and we talk and I tease her. She responds appropriately. I say 'Cynthia you're going to bed.' She screams. I really think she understands. Deep in my soul I believe. The other day was her birthday and the boys and I sang happy birthday and cheered and yelled and she was so excited. She laughed. I said 'Today is your birthday and you are 20 years old and when are you going to move out and get a job.' Everyone was laughing including her. It is just something I feel within me. There is nothing scientific I can say that would prove it. They say she has the mentality of a 9 month old. I say they are wrong. She has learned to feed herself and that was real easy and fast."

Marilyn gloats over the special relationship Cynthia has with Monnie. When her husband walks in Cynthia has "stars in her eyes." "There is something about Monnie. I can walk into the room and she'll say 'umm.' Monnie walks in and 'ahh!' I guess it's because mothers are the ones that discipline and force you to eat your vegetables. They tell you you have got to go to bed but fathers, that's different."

I asked Marilyn how Cynthia has affected her relationship with Monnie: "We're just close, solid. I don't know of any other man that would take in a child like Cynthia and willingly do the things he does. He has to get up and bathe her. Cynthia usually craps all over the bed and he cleans it. He feeds her breakfast. He gets the boys up and dressed and fed and on and on. I mean people ask him--you know this is not your child you don't have to do this. I just love him more because of what he does and how he is with Cynthia. I really appreciate him."

Marilyn's mother lives in Florida but she is in daily contact with her on the phone. Her mother was always worried that Cynthia would tie her down. Marilyn thinks that Cynthia has affected her life but it's "not so confining:" It has probably added to it. Monnie and I sit down and think and talk. Suppose we didn't have the kids? What would be be doing? Would we work this hard? We might be drug addicts. The kids are a responsibility. When someone is dependent on you you can't be a drug addict or not be responsible. They keep us going. I want my kids to know that you work for what you get and there is nothing wrong with taking a chance as long as you are willing to deal with whatever circumstances you get in. Our lives are a big chance. We survive and we work hard but we have meaning in our lives."

Cynthia has been tested by professionals but Marilyn and Monnie don't care anything about the test results now. In the beginning it was important because they wanted to get her in the right program. Now they don't care what other people think about her. They don't care what the people at the CP center say about

her mental age. As Marilyn said: "I don't care because I know what I got going with her."

When the Brabhams first knew Cynthia the doctors told them that Cynthia would not live long. She was susceptible to infection and they predicted that she would be in and out of the hospital all of her short life. That has not come to pass. The Brabhams listen to professionals now but they take what the say cautiously. They think that doctors are prejudiced toward her. Once they took her to the Scottish Rite Hospital in Atlanta to have surgery done on her hands to straighten them but they wouldn't because as Marilyn says: "They didn't think it was worth doing it on her." According to Marilyn they and the other professionals don't give Cynthia the benefit of the doubt. They always think about what's wrong with her rather than what's right. Her skepticism with the CP center is a little different. They have been trying to place Cynthia in a work setting. Marilyn is skeptical. "What kind of work is Cynthia going to do? It's all right. If they come up with something that's suitable we will try it. But I want to see what it is."

Cynthia goes to school and after school comes and sits in the reception area of Monnie's beauty shop. People who come to the shop know Cynthia now and enjoy her. That gives Monnie and Marilyn great pleasure. Nobody is scared of her and no one has stopped coming to the shop because she is there. They still have problems finding a sitter.

Half in jest, Marilyn compared Cynthia with her other children. She said that she is the easiest one she has. She doesn't have to tell her to leave that alone, or get out of there, or don't climb a tree, or be careful on the bike. Marilyn's relationship with Cynthia has changed. She no longer thinks of herself as Cynthia's advocate, "I'm her mama."

Marilyn leaves her home at 6:15 every weekday morning. She usually is not back home until maybe 8:00 or 9:00. Sunday is the only day they both have off and they usually just stay at home, too tired to do anything. Marilyn wishes that there were others involved in Cynthia's life to take her overnight so she and her husband might have some more time to themselves and a break in the routine but, as Marilyn says: "We are doing just fine."

I asked Marilyn what might be in her background that would lead her to develop the relationship she has with Cynthia. Marilyn has trouble coming up with anything specific. Her family wasn't overly religious and no one in the family was involved with anybody with a disability. The only thing Marilyn could come up with was: "I guess that it all comes back to my mama always saying you treat people like you want somebody to treat you. Mama always helped the other people who were poor. She got canned goods for the needy at Thanksgiving and that kind of thing. I guess it was just embedded in me."

I asked Marilyn if the question "Why do you do it?" was annoying to her. She said: "Yeah--because I don't think about why and usually when a person asks you know they are thinking that I would be better off if Cynthia was in a nursing home."

The Brabhams don't get paid for having Cynthia in their house. They prefer to pay for her as they would for any family member. The company Marilyn works for provides family medical coverage but recently they have been balking over the medical expenses for Cynthia and now are refusing to pay. They told her that having Cynthia at home was her choice. She could be in an institution or the government could be paying her expenses. They have taken away her coverage.

Marilyn thinks that besides companionship and being a part of the family, Cynthia gives a lot to her family: "I don't have to worry about my boys growing up calling people names. My husband doesn't feel that he just doesn't want to be around handicapped people anymore. There is so much that we get out of it. Building my children's character and letting people know that just because somebody is handicapped it's no big deal."

Marilyn worries about what is going to happen to Cynthia when she and her husband get old and can't carry her anymore. She can't see her going back to an institution because she doesn't think that Cynthia could handle it.

The Brabhams don't think what they are doing is remarkable. What amazes them is that our society allowed Cynthia to live her childhood in a nursing home. They think that the government has provided a "give me" mentality. We would rather have the government pay thousands upon thousands of dollars a year to keep someone away from everyone else than to do what's right. To them the question "Why are you doing this?" is silly. What they want to know is why more people aren't like them?

Denise and Robert Eason and Kenneth

Denise Eason met three-year-old Kenneth through Frankie Lewis, one of the two staff people in the Macon/Bibb Citizen Advocacy Office. As Frankie and the other staff do, Frankie was going through a list of people who might be possible advocates for the boy who, at the time, was the only child resident in a large and impersonal total care nursing home. At the age of 18 months Kenneth had accidentally consumed a large dose of poison leaving him profoundly retarded, blind and totally paralyzed.

Denise came to Frankie's mind because of something she had said. Denise and Frankie both had a child in a pre-school program and were casual acquaintances. One day someone made a comment about a "Psycho-Educational Clinic" in the area. Denise said, "What a terrible name for a place. Couldn't they call it something else? I would never send my child to a place with that kind of a name!" Frankie made note of that, thinking that Denise had a way of seeing the world that might make her a great advocate.

Denise and Frankie were having lunch the day that Frankie told her about Ken. When Frankie said he was in a nursing home her immediate reaction was: "Now what is a three-year-old doing in a nursing home?" Frankie asked if Denise would be Ken's advocate. Denise didn't know what an "advocate" was but according to Denise, Frankie explained that it was "a person that saw to it that people with disabilities got their rights, they make sure they get their fair share, that they get treated like

they're human." That afternoon Frankie took Denise over to see Ken. Denise, upon seeing the boy said, "My God, I would like to take him home with me" to which Frankie responded: "Why don't you?"

Denise told Robert, her husband, but according to her, he didn't pay much attention, since he is used to her "wild ideas." The next day, he and their two boys went to the nursing home. Robert's reaction was the same as Denise's: "Why is a three-year-old in a nursing home?" It was either Denise or Robert who made the comment: "We should take care of our own." The Easons are black and so is Ken. Denise told me of the tradition in the black community of having relatives cared for at home. The family was the unit to take care of the elderly and the chronically sick, not some impersonal institution.

Kenneth's connection to the Easons involves another event in the life of the family. About a year and a half before Ken came into their lives Denise had a miscarriage. Denise was five months pregnant. Everything had gone well to that point. She could feel the baby moving. As she put it: "I wanted this baby real bad." Both of their children were from previous marriages. Everyone was excited. They bought clothes and a baby bed and they had a hope chest. Denise said she almost died during the miscarriage and suffered severe depression afterwards. She wouldn't go out and would have nothing to do with her friends.

She came out of it and tried to lose her sorrow in work. She was working three jobs. When Denise saw Kenneth she said that this was the baby that God had meant for her. Denise, who is a

strongly religious women, believes that her baby died for a purpose. God was testing her, giving her a challenge to make her stronger so that she would have the courage to care for Kenneth. Some of her friends were skeptical of Denise and Robert's decision to enter into Kenneth's life: "A lot of people look at me strange because I would adopt a child that had severe disabilities. The way I look at it is that they are the ones that should be adopted. The others, those that are normal, they are going to survive, at 18 they can walk away and start their own lives. Children with disabilities don't have that kind of chance. They don't have people to love them. Just four walls. They need somebody more."

On April 5, 1987 at 9:00 a.m., Kenneth left the nursing home to come home with the Easons. As they left, Bob Eason, Denise's husband, said to his wife, "...this is a joyful moment that I never want to forget...He'll never be institutionalized again." Kenneth's mother was supportive of her son being with the Easons. She had been unable to care for Ken since the accident. The Easons have not adopted Kenneth yet. They don't want to push the mother or make her feel bad. Denise is giving her a lot of support. "I give her hugs. I hug her when I see her and I hug her when she leaves. I let her know that I don't look down on her because she did this to Ken. Denise, who operates a day care center, enrolled Ken and he was put in a class with other children his age. According to Denise, family and friends have embraced the little boy they have taken into their home, and Sandy and Robert, the Eason's other two children willingly help

their parents with Ken. Robert is getting a variety of services from private practitioners that he wasn't getting in the nursing home.

According to the doctors, Kenneth will never be able to communicate and cannot sense his environment. But Denise has a different view: "I feel he knows I'm there. I feel he knows that he's not in a nursing home anymore. On the way out the door of that place I said: 'Hey you are going home.' He said, 'ohhh, uhhh' and that was the first response he ever made to me. He didn't cry, now he cries. He has emotions. He lets you know when you are hurting him or when he wants you to hold him."

The doctors told Denise that Kenneth is blind, but she and other family members don't believe them. They claim that although he doesn't follow your finger he sometimes moves his eyes in the direction of a voice. They also interpret tongue movement changes when he is talked to that he can hear. The doctors say he is deaf. Denise tells of events that indicate to her that Kenneth can recognize Robert.

Denise owns and runs a day care center and is a certified tax preparer. Robert supervises roofers. Denise is an active Eastern Star with all her degrees and her husband is in the process of starting a Masonic lodge. They travel a lot. Family helps out with Kenneth. Recently Ken was admitted to the hospital because he wasn't gaining weight. He will be home with the Easons soon. In the meantime Robert and Denise stay in shifts at Kenneth's bed side.

While some of Denise's friends warned her that Kenneth would be a burden on her marriage, Denise has found the opposite. "He has brought joy to us. My husband and I are closer as a result of Kenneth." With pride in her husband, she tells of the affection that he shows toward the boy and the love he has for him. Denise loves Robert more because Kenneth brings out the kind and affectionate man Robert usually hides.

Kenneth takes a lot of Denise and Robert's time but they are quick to add, not more than any child would. Denise told me: "I sacrifice a lot for him. Each day I wake up and give him his bath, brush his teeth, feed him his breakfast and get him to his program. It has done something to me. It has drawn more love out of me that I never thought I had. I feel he needs me. I just feel if I did not do the things I'm doing he would die."

Of course there is the chance that Kenneth will die soon but Denise and Robert can live with that. As Denise put it: "I will know I did all I could for him. I feel like I could pick back up and go back to doing what I was doing... I feel that everybody that lives should have a purpose in life. Sometimes you should do things for others. That's what counts in my life now."

Kenneth has been to the zoo, Six Flags over Georgia, and many other places. The Easons take him wherever the family goes. They treat him like a normal son. While Denise is well aware of the prognosis for Kenneth she says that she also believes in miracles. She sort of knows that he will never talk, or walk or see but she will not give up the slim possibility that he might. Denise says, "I want to keep believing because I believe that if

you have a positive attitude and you keep believing in something it might happen. If you don't believe, there is not possibility."

Clete Bergen and the Benjamin Family

The story of the relationship between Clete Bergen, a white 40-year-old Savannah lawyer, and 38-year-old Sammy Benjamin, a black severely retarded son of a women who has lived a life filled with tragedy, is complicated--not only in terms of the events surrounding the relationship but the meaning of it as well. Unraveling it provides a different twist to the meaning of "we take care of our own," a meaning that is deeply ingrained in the history of the area and the relationships between blacks and whites.

Clete's relationship to Sammy is deeply about Clete's relationship to Elizabeth Benjamin, Sammy's mother. While Clete was growing up Elizabeth worked for his family as a domestic. Through that position, and due to the fact that Clete's mother was ill, Elizabeth and Clete became very close. As he puts it: "She practically raised me. She was always there." The Benjamins and Bergens lived then, as they do today, close to each other in a section of coastal Georgia outside of Savannah called Coffee Bluff. The section the Benjamins live in consists of small pieces of land which were the result of the division of planations after the Civil War. Clete lives in a large modern house that his father, who was an architect, designed. The house overlooks a beautiful large waterway leading to the Atlantic Ocean. Unlike the houses in the expensive developments in the area, Clete's

house is not ostentatious. Sea breezes bathe the screened in living area in the back with cool air. Coffee Bluff is gradually being converted to a rich suburban enclave. Both the Benjamins and the Bergens are old timers in a changing area.

During the period that Clete was at college and law school he lost touch with Mrs. Benjamin. She fell into difficult times. Both she and her only son, Sammy, were institutionalized in the mid-70s. She was deeply depressed.

At the same time her daughter, Marie, got married and in a short period of time had five children to support. Her husband was abusive and she, in spite of her husband's objection, went to Clete to get help with a divorce. Maria told Clete that she was afraid of what her husband might do if she went ahead with her plan. Clete told her that it was a common fear. Three days after the divorce her husband came to her dilapidated shack and shot Maria dead in the presence of the children. Clete was called in the middle of the night and visited the devastating scene.

Elizabeth's sister cared for Maria's four young daughters and a son at first. Elizabeth was released and returned to her three room, no utilities, clapboard shack in Coffee Bluff. Soon she had her grandchildren with her. Clete kept track of the children and visited Elizabeth at her house. He observed the substandard living conditions, the three girls sleeping in one bed and the boy sleeping on the couch, and vowed to find something better for the family. As he said: "There was such basic need there. She raised me. You pay back what's been done for you."

It was a matter of coincidence that Tom Kohler, director of the Savannah-Chatham Citizen Advocacy office, called Clete about Sammy Benjamin. Tom had no idea that Clete knew the Benjamin family. He knew that Clete was active in community affairs, and he had a "protege" that grew up in in Coffee Bluff he was looking to match with an "advocate." Sammy had been institutionalized for eight years and Mrs. Benjamin had lost contact with her son. She thought he was dead. When Tom called Clete, Sammy was in a group home with five teenage boys who were also labeled retarded. Soon after Clete's talk with Tom, in late 1981, Mrs. Benjamin was reunited with her son. Clete was officially Sammy's advocate, but more accurately his commitment to doing something for the Benjamins as a family was ignited by Sammy.

Mrs. Benjamin wanted to have Sammy live with her. Given the size and condition of her house that was impossible. In the meantime Sammy was transferred to a nursing home about an hour south of Savannah. When Clete and Tom went down to visit him they found him tied to a chair with feces all around and bruises on his back. After that visit they had Sammy transferred again, this time to a nursing home two miles from his mother.

Tom and Clete, intent on getting new housing for the Benjamins, had a number of potluck brainstorming sessions with various people in the community to try to figure out how they could get a proper house for the Sammy and his family. Through various means, including having the actual construction done by the voctech students free of charge as a class project, a 2,000-plus square foot house was built for the family close by their

old home. It is a gorgeous brick and wood house, a source of both family and community pride.

When the house was complete the Benjamins, without Sammy, moved in with much celebration. There was some reluctance on the children's part as to whether they wanted to live with their retarded uncle whom they didn't even know. David, the oldest child wasn't sure he wanted to share his new bedroom. But Mrs. Benjamin wanted Sammy to come home. Sammy Benjamin moved into his mother's new house on October 30, 1985, just in time for his birthday.

According to Elizabeth, Benjamin, Clete, and Tom, having Sammy at home has worked out well, better than anyone's expectations. The children seem to accept Sammy and participate in his life. Clete says that Sam has brought the family closer together and has given Elizabeth a new purpose in her life.

When I visited the family Sammy seemed exhausted. He has gotten into the pattern of staying up most of the night watching television and then sleeping all day. Elizabeth seemed tired also. She told us how difficult it was watching over teenagers and Sammy too. When Tom and I visited with Clete the state of the family was discussed. Clete keeps in touch with the Benjamins and is committed to staying involved in their lives. At the end of the week he is going to drop in and have a long talk with Elizabeth to see what's going on, and whether he can provide some advice or other help. The way Clete sees it, he owes what he did and is doing for the Benjamins. Clete is just taking care of his own.

* * *

Citizen advocacy in the programs I visited is anchored to a well thought out and comprehensive theory about life and the human service system. The staff see bureaucratic human service organizations as eroding the natural good will and support that is available in the community. The concept of citizen advocacy isn't just a big brother program that helps people who are disabled. It's a way of putting people in touch with basic values of community and provides an alternative to what is seen as the impersonal over-professionalized way human services are delivered. While bureaucratic care dehumanizes, citizen advocacy affirms human value and the strength of the community. As a publication from the Macon/Bibb Citizen Advocacy office expressed it:

> ...we have the opportunity to put our own citizenship to use. The acts of extending friendship, offering opportunities to participate in real community life and sticking together as neighbors, strengthen the glue of democracy that hold our way of life together.

One newsletter published the following about citizen advocacy relationships:

> RELATIONSHIPS ARE ABOUT
>
> LOVE vs. LAW
>
> PASSION vs. POLICY
>
> RESPONSIBILITY vs. REGULATIONS

While the program has a theory of community and a preferred way of reaching out to disabled human beings its approach to the human services is not negative. The staff is outspoken in their condemnation of institutional placement for any person with a disability but their message is overwhelmingly positive. It's about building a different society, about the positive things that human beings can do one to one with each other. This is apparent in the tone of their inspirational newsletters;

> CITIZEN ADVOCACY is about two people paying attention to one another...
>
> CITIZEN ADVOCACY is about dignity choice, celebration, compassion and hope...
>
> CITIZEN ADVOCACY is about intelligent loving with an informed heart...
>
> CITIZEN ADVOCACY is about inclusion in the world of community...
>
> CITIZEN ADVOCACY is about focusing on people's capabilities not their deficiencies...

The staff, and to varying degrees the advocates, openly celebrate their values. They have a community in which the acceptance of developmentally disabled people is the norm. Inspirational quotations, like the following from the Rev. Martin Luther King, Jr., are displayed in newsletters and in the offices.

> The true neighbor will risk his position, his prestige, and even his life for the welfare of others. In dangerous valleys and hazardous pathways, he will lift some bruised and beaten brother to a higher and more noble life.

The staff of Georgia Citizen Advocacy has developed guidelines and procedures for various aspects of their organization including the development of "advocacy/partner" relationships. They have an orientation for advocates, but over time staff have come to see the matching and ongoing support of such caring relations as more of an art than a science. They rely on their personal experience and common sense. Advocates often have their orientation over lunch with the coordinator discussing the philosophy of citizen advocacy and encouraging the advocate to suspend stereotypes about the type of person they are about to meet. Potential advocates are appealed to on the basis of their pride in community and basic values about "taking care of our own." The advocate is guided to evolve a relationship with the protege that feels right to both parties. The advocate might function in one or all of the following capacities: monitor services being provided to the protege, be a spokesperson for the protege especially around issues of rights, assist the protege with practical problem solving, assume court-appointed responsibility for the protege, handle the financial affairs of the protege, adopt the protege, be a companion or friend to the protege.

Propositions and Generalizations Sparked by Georgia Visit

1. Programs for the developmentally disabled vary in the degree to which they represent the values and culture of the area they are developed in. Georgia Citizen Advocacy capitalizes on aspects of Georgia culture--neighborliness, helping your own, and independence--and this, in part, explains its success.

2. The staff's relationship to their communities is an important aspect of a program's success. In Savannah and in Macon the staff are hooked into the community in a meaningful way. Some of the staff are "natives" in the most profound sense of the word. They grew up in the city they now work in and have many ties and connections. They use those ties to build relationships. I got the sense that Georgia Citizen Advocacy was very much an indigenous concept and institution. Thinking back on Vermont I got much more the sense that the residential programs I visited there were more "imported."

3. When a non-disabled person, who is well integrated into the community--who has many relationships and ties in the community--forms a relationship with a person with disabilities, the likelihood of the disabled person forming other relationships increases markedly.

4. Organizations that have and know how to maintain a strong ideological commitment complete with deeply felt values and beliefs about the worth of developmentally disabled people and non-disabled people's relationship to

them, are more likely to generate activities which lead to people living well than those that don't.

5. People who are in meaningful relationships with people with disabilities grow to take them for granted. To them, what they do is not heroic or does not require tremendous sacrifice, it is just part of their lives. People who relate to such people as unusual or as exceptional help to perpetuate the norm of not having such relationships.

6. People who have relationships with people with disabilities derive a great deal of gratification from them. They do not see them as one-sided--that they are the ones that are doing all the giving--but rather as reciprocal.

7. Meaningful and lasting relationships between disabled and non-disabled people can take many forms. What is important is the sentiment behind them rather than the specific form the relationship takes.

For more information, please contact:

Georgia Advocacy Office, Inc.
1447 Peachtree Street, N. E.
Suite 811
Atlanta, GA 30309